Palliative Care Services Public Engagement Report August 2020

In the boroughs of Brent, Hammersmith & Fulham, Kensington & Chelsea and Westminster.

Contents

Palliative Care Services Engagement Report

This document provides an overview of the feedback we received during the period of engagement and involvement we held regarding the future of palliative care services in Brent, Hammersmith & Fulham, Kensington & Chelsea and Westminster in February 2020.

This was an engagement period to hear the views of the public and not a public consultation. If CCG Governing Bodies decide to make 'substantial' changes to services there would be a full public consultation. If you have feedback on this report we'd like to hear from you, please email nwlccgs.triborough.palliativecare@nhs.net or call 020 3350 4366.

Thank You

Thank you to everyone who has been involved in sharing their feedback around the palliative care review. We understand that this is an emotive issue and thank you for your on-going involvement in this process.

Current status of the review

The recent coronavirus outbreak has called for the NHS to prioritise it's resources to handling the health response. As a result the palliative care review was put on pause and the in-patient beds at the Pembridge Hospice in North Kensington have been used as part of the coronavirus response.

The situation is being monitored on an on-going basis until the outbreak has fully stabilised.

What have we been doing?

Since December 2018 we have engaged; local patients, families, carers, residents, the voluntary and community sector and patient representatives across the four boroughs. We have approached this engagement in 3 periods.

1. 'Call for evidence' - launched locally asking anyone with a view on palliative care services including service users to tell us about their experience, including people working in healthcare services

Purpose: inform the Independent Review – accessed here.

2. Workshops – In Autumn 2019 workshops were held across the boroughs to understand the experience of the end to end pathway. Workshops were on 'Access', 'Care' and 'Bereavement / aftercare'

Purpose: in-depth conversations on the whole end to end pathway and information to feed into future potential scenarios.

3. Potential Scenarios - Public engagement

Listening to feedback from the public and stakeholders following the public workshops, we launched our 'potential scenarios' to the public for discussion and feedback.

Purpose: to work in partnership with the public to design future potential scenarios and to hear the public's view on potential scenarios designed by the CCG.

Patient and Public Palliative Care Working Group

Following feedback from the public that they would like more involvement in this programme of work and the development of solutions to the challenges facing local palliative care services, the Public and Patient Working Group was formed.

This followed an open recruitment process which was advertised online and during the public workshop events. The group has a diverse membership, including carers, homeless end of life coordinator, ex-commissioner, Healthwatch representation and local authority scrutiny member.

Involvement options

In February of this year we engaged with the local community across the 4 boroughs on a number of 'potential scenarios' which was published in an 'involvement document' which set out the current thinking about how we may organise specialist palliative care services in the future.

The 4 scenarios we wanted to get feedback on from the local community and staff were:

Scenario 1—Services remain the same.

This scenario would keep all palliative care services as they are including the re-opening of the inpatient unit at the Pembridge, subject to the appointment of a palliative care consultant. In-patient, day and community care services would continue as they are.

Scenario 2- Some improvements to day and community services with in-patient services remaining the same.

This scenario would keep in-patient services as they are now, including the re-opening of the inpatient unit at the Pembridge subject to the appointment of a palliative care consultant.

Community services would also be standardised to 5 days week. This scenario would also lead to some improvements in the co-ordination of out of hours advice.

Scenario 3—A re-design of all elements of palliative care services.

This scenario would see in-patient services delivered from four rather than five sites but without reducing the number of beds that the NHS funds.

This would enable CCGs to fund enhanced community services 7 days a week, with 24/7 admissions for patients. It would also provide an out-of-hours nurse visiting service and Hospice@Home available to all.

Scenario 4—A re-design of all elements of palliative care services including access to a new nurse-led inpatient service.

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds. CCGs would then fund enhanced community services.

Patients who do not have complex medical needs, but whose preference is to die in a hospice environment could receive nurse-led care at a bed in North Kensington provided by the Pembridge Palliative Care.

Gathering feedback from local people

We gathered views from a wide range of people and organisations, including:

- Patients
- Carers
- Local residents
- Service user groups
- Patient and Public Working Group
- Local Patient Reference groups (PRGS)
- Clinical Reference Group
- Healthcare staff across the hospices involved in the review
- Local residents
- Local MPs
- Local councils and councillors
- Local Healthwatch groups
- GPs
- Palliative Care consultants
- Campaign groups

The channels we used to engage with local communities were:

- NHS CCG channels in each borough— website, social media, newsletters, and posters
- Local focus groups
- Citizen panel—1500+ sent survey to complete
- GP communications & screens
- Patient & Public Working Group, NWL lay reps and PPG groups
- Posters in hospices
- Social media platform Next door
- Local stakeholder communications and follow up
- Communications through local council channels
- Posters in libraries
- Mailing list updates
- Palliative care Healthcare professional workshops
- Local meeting attendance

Local engagement meetings:

Date	CCG	Meeting title	Venue	Attendance
12 Feb	Hammersmith & Fulham	People Arise Now	The Minaret Community Centre, 303 North End Road, London, W14 9NS	60 women attended the event predominantly from a BME background with an interpreter (Somali language)
17 Feb	Central London	Breathe Easy	Ada Court, Maida Vale, W9 1TD	19 attendees
18 Feb	West London	WLCCG Patient Reference Group	Venture Centre	14 attendees
24 Feb	Hammersmith & Fulham	Focus group	White City Community Centre	7 attendees
25 Feb	West London	Focus group at Ethiopian Women's Empowerment Group	Bay 20	26 attendees
25 Feb	West London	Focus group at the French African Women's Association (FAWA)	Canalside House	31 attendees
25 Feb	Brent	Focus group	Welford Centre	22 attendees
26 Feb	West London	Focus group with Age UK	Pepper Pot, Thorpe Close	15 attendees
26 Feb	West London	Drop in day	West way	5 attendees
26 Feb	Hammersmith & Fulham	Focus group with alcohol and drug service	Lytton Community Hall, North End, Crescent	10 attendees of patients, service users & CVO reps
26 Feb	Hammersmith & Fulham	Focus group with Yarrow	Askew Road, Methodist Church	15 attendees of learning disabilities, families and carers
27 Feb	West London	Workshop	Al Manaar, The Muslim Cultural Centre	16 attendees
27 Feb	Hammersmith & Fulham	Mungo's charity for Homeless people	Seminar Room, Richford Gate Medical Practice, Richford Street, W6 6H	18 homeless and rough sleepers and CVS Reps
3 March	Hammersmith & Fulham	Patient Participation Group (PPG)	St Pauls Centre, Hammersmith	16 attendees patients, local residence and CVO reps
9 March	Central London	Church Street Community Champions	One Westminster, 37 Chapel Street	11 attendees
9 March	West London	Workshop	The Mosaic Rooms, 226 Cromwell Road	17 attendees
11 March	Central London	South Westminster Neighbourhood Network Quarterly meeting	The Abbey Centre	14 attendees
11 March	West London	Workshop	Baden Powell House, 65 – 67 Queens Gate	10 attendees
11 March	Brent	Focus Group	Community Enterprise Centre	4 attendees

Themes—A summary from the survey, email correspondence and local events.

Dying in dignity

- Residents were pleased to see that the CCG were engaging the public on this important issue
- Agreement from all that palliative care services are vitally important to local communities
- A feeling that inpatient beds should be available in each borough to enable this

Communication & awareness

- As a society we need to do more to talk about death and dying
- Many people are not sure where and how they access palliative care services
- Care planning and discussions should start earlier
- More could be done to equip health and care professionals to talk about death
- Feedback from events was that residents valued the time to discuss these issues and have their voices heard

Capacity

- Residents want to know more about capacity in the system (now and in the future)
- Residents want to be reassured that there is capacity in the system for patients who require an inpatient bed to have one in the future
- Will the same number of beds be made available in other hospices—confusion around the term 'bed days'

Review process

- Residents want to know more about the evidence the CCG is using
- Queries about the data used in the Independent review of specialist palliative care services —clarification around the 48% figure which is the number of patient deaths seen by palliative care providers
- Queries on the evidence base for Brent as not covered by the Independent review

Inpatient services at Pembridge Palliative Care Centre

- Strong local desire to maintain inpatient services at Pembridge and opposition to the suggestion it would close
- Local deprivation in Hammersmith, North Kensington, North Westminster and South Brent—the importance of keeping services in these areas
- Pembridge is the only inpatient NHS provided service in the North West London area
- Area recently recovering from the Grenfell tower fire, further cuts to services perceived inappropriate.

Improving access to services

- Agreement that palliative care services need to reach more people
- Different service design can help improve access for particular groups (e.g. homeless, BAME groups, greater support for carers)
- Feedback from some BAME groups—preference is to die at home with family
- Some people may be deterred from the perceived 'religious affiliation of other hospices. A need to create a religious and spiritual space for all.

Engagement

- Residents wanted more information to understand the potential scenarios—too complex
- Feedback that the survey included too many closed questions
- Inconsistency in engagement activity across boroughs
- While being clear in all communications that the CCGs are not in a consultation phase there was still confusion that this was a consultation
- People feeling that they have made their views clear but are being asked the same questions again

Staffing

- Public wanted to know more information about why a consultant could not be found
- Public wanted more information about how the potential scenarios would help to solve workforce shortages
- Public wanted more information about staffing in the future

Funding and finances

- Residents wanted to have more information and detail about finances—how the scenarios would be funded
- Confusion about scenario 4 and how this can be afforded
- Residents wanted to be reassured that the review was not a cost saving exercise

Travel and transport

- Residents that live in the boroughs involved in the review are less
  likely to own a car and would likely be reliant on public transport making additional travel more challenging
- Issues around patients, friends and family members having to travel further to access services
- Many carers may be elderly and frail
- The cost of private transport if residents need to take taxis

Need for change

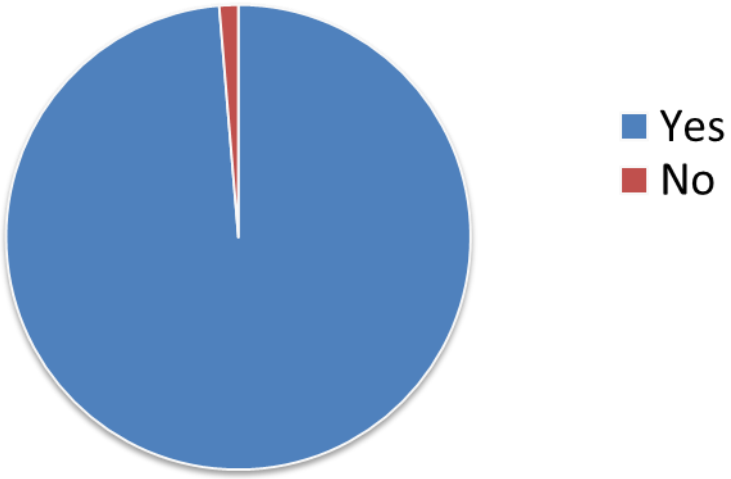
- While many comments demonstrated that residents were happy with local services, many also reflected a need for change in the system
- They referenced how it is important to improve access so more people receive care in their preferred setting.

Engagement

- **200** people completed the survey in the Involvement Document
- **20** local engagement events were organised
- Over **300** residents attended across all 4 boroughs.
- **5** written responses from key stakeholders
- A full appendix of all responses to the surveys is available at the end of this document.

Survey results

Q: Do you agree that we need to help more people to access palliative care services and to make what is available more consistent for everyone?



Answer Choices	Responses	
Yes	98.68%	150
No	1.32%	2
	Answered	152
	Skipped	40

Q: What is the most important thing that palliative care services offer to those that need them?

The palliative nurses are always available to help
A timely and holistic service
End of life support for the individuals and their families.
The right help at the right time in the preferred place
Support and to have all their needs met in a comfortable supportive and relaxing "Caring" and clean environment.
Relief from pain
Dr's and Nurse's monitoring symptoms. Meeting and supporting with other patients with terminal illnesses. Art and quizzes and story time which helps with communication and sharing with other patients, i.e. having a little fun which eases your diagnosis. Respite for family, carers. Being made feel worthy and loved.
The care and support vulnerable people require
pain control and symptom control reassurance and advice.
Symptom control advice
Inpatient beds in our local area
kindness, specialist care, pain relief
Pain control
a caring bespoke end of life approach, above anything concerned with cost and saving money.
Easy access and choice
Knowledge care attention

Access to compassionate and holistic specialist support. I support many unpaid carers of people in the end of life or later years of years in need or accessing palliative care support. And my experience is that specialist palliative care providers such as hospices provide a single point of contact and comfort for their patient and immediate family who often struggle to navigate a health and social system that is complex.
Individuals should be able to remain living independently in their own accommodation when possible
Support
Support to the individual - dying with the family
Expertise, clinically and in person centred terms, practical services, which are person - centred, psychological support, information and advice covering all needs, leading to a sense of security and alleviation of distress and fear for the Individual patient and those close to them
End of life
Helping people at end of life stage to get proper support, physically and more importantly mental and psychological
Specialist care when they have an incurable illness.
Helping to cope with life as it comes to the end.
A caring, knowledgeable nursing of the patient, and support to the carers.
pain relief and support at home
Confidence
Total support for the whole family or the patient if there is no family.

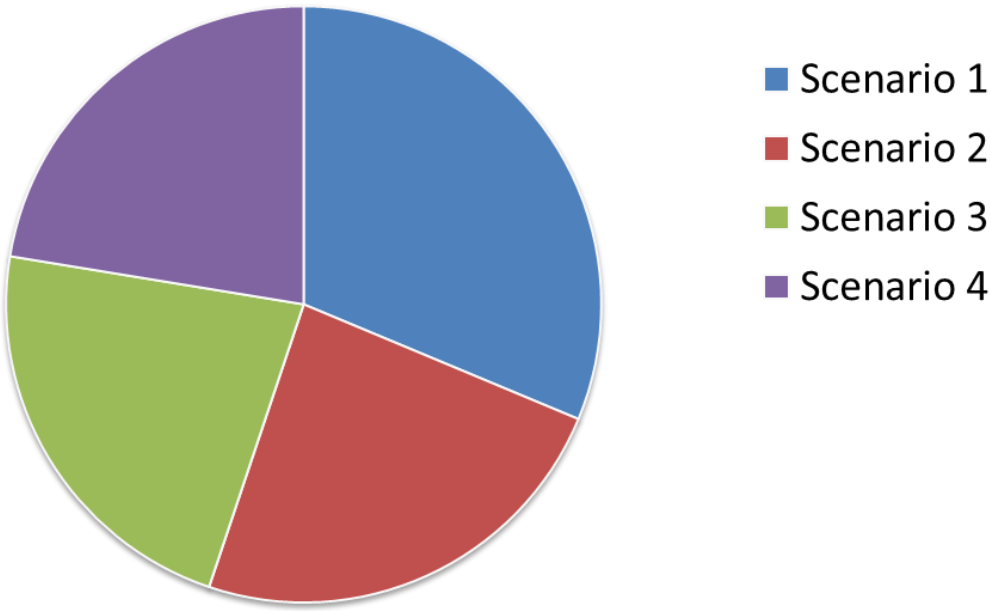
Q: What is your preferred potential scenario?

Scenario 1—*Services remain the same.*

Scenario 2- *Some improvements to day and community services with in-patient services remaining the same.*

Scenario 3*—A re-design of all elements of palliative care services.*

Scenario 4—*A re-design of all elements of palliative care services including access to a new nurse-led inpatient ser-*



Answer Choices	Responses	
1	31.16%	42
2	23.91%	30
3	22.46%	31
4	22.46%	31
	Answered	134
	Skipped	58

Feedback on potential scenario 1: Summary:

Comments	Concerns	Suggestion to improve the solution:
• *Many of the comments highlighted local desire to have inpatient hospice services in their local area* • *Many of the comments expressed a wish to keep services as they are* • *Some comments highlighted how Pembridge Palliative Care Centre is well located in terms of geography* • *Comments highlighted the need for local services when next of kin are often aren't independently mobile*	• *Many comments expressed concern that if services do not change there will be no improvements in increasing access to palliative care services* • *Many comments highlighted how Pembridge Palliative Care Service was underutilised* • *Some comments highlighted concerns with sustainability and fragility if the inpatient unit a Pembridge Palliative Care Service is dependent on finding and maintaining a consultant*	• *A central point of information* • *Open an end of life hub to coordinate palliative care in the community including: referrals to the different services and fast track discharges from acute* • *Raising awareness of palliative care services*
• *"It is necessary to keep Pembridge as an inpatient service as the only such service situated in the four boroughs"* • *"This review comes at a critical time for Pembridge Palliative Care centre and the local attachment to this service should be dealt with careful"* • *"This seems ideal and gives people the option of inpatient care close to where they live"* • *"Everyone would like to keep Pembridge operational but it was underutilised, and the stress on other hospices since it has been non operational has been manageable suggesting that it is possible to manage without it."*	• *"This scenario is not viable if keeping Pembridge opened means that there can not be improvement to inconsistency to services such as Hospice@Home and community care provisions"* • *"This would be ideal. However, I hear the service is under used, therefore it is understandable to spread the service to other hospices"* • *"Once again the Pembridge inpatient unit will be dependent on one consultant - not sustainable and there does not seem to be more resources for community care and services"*	• *"Open beds at Pembridge for local residence and commission all those providing palliative care in community against appropriate outcomes. Open an End of life hub to coordinate palliative care in the community including: referrals to the different services & fast track discharges from acute"* • *"The commissioning of specialist palliative care should be used to create a more equal service across the patch."* • *"More information should be available in GPs surgeries"*

Feedback on potential scenario 2: Summary:

Comments	Concerns	Suggestion to improve the solution:
• *Many of the comments expressed that they liked how this scenario allowed the inpatient facility at all the hospices involved in the review to stay open*	• *Some comments were unsure if this scenario would result in Improvements* • *Some comments highlighted concerns with sustainability and fragility if the inpatient unit a Pembridge Palliative Care Service is dependent on finding and maintaining a consultant*	• *Improved data collection* • *Raising awareness and education around services*
• *"Probably the best option although I feel there could be more ambition community services and provision."* • *"This achieves retention of Pembridge for in house services and slightly improves and makes more consistent other services, so unless more funding can be obtained it is my preferred outcome."* • *"Happy to have Hospice near to me* • *This service works well and with small changes can be even better"* • *"Ensure coordination of services"*	• *"The concern is over the struggle to recruit a consultant and the fact that this option may not be enough to put an end to the inconsistency around access to community services including Hospice@Home"* • *"lack of appropriate staff could prevent the service being able to cope"* • *"We also need different levels of service to be more available, e.g. hospice at home"* • *"Why no mention of extra investment as in 3 and 4?"* • *"this is tinkering but not making the changes for the long term"* • *"Same problems as Scenario 1. Also no Increase in capacity and scope."*	• *"Public knowledge and education about how services can be optimally used. Transparency with public, staff and clear information about wrap-around service for public and staff"* • *"Provide monitored evidence of the demand and capacity for hospice beds and also reflect how many people have wished for access to a hospice - both current need and projected aging population."* • *"We need to make our services more attractive to professionals so all vacancies are filled by trained and committed specialists"*

Feedback on potential scenario 3: Summary:

Comments	Concerns	Suggestion to improve the solution:
• *Many comments stated how they were supported of extending community and out of hours care but not at the expense of the inpatient unit at Pembridge Palliative Care Centre being closed* • *Many comments felt this was a good option to improve services* • *Some comments referenced how they were supportive of this scenario as it would Increase the number of patients able to access specialist palliative care services*	• *Many comments referenced that they were concerned with the lack of inpatient beds in this scenario* • *Many comments were concerned that local inpatient beds would not be available* • *Many comments were concerned that all the providers for inpatient services are from the voluntary sector and not the NHS* • *Many comments were also concerned that this scenario would result in longer travel times* • *Many comments were concerned with changing a system that they felt worked well already*	• *More resources so improvements in community care could take place will keeping all 5 inpatient units open* • *Looking at a shared model of consultants across the patch* • *Community transport to support local residents and patient to visit other hospices at no cost to them*
• *"This seems like the most desirable option. A comprehensive service with a far higher number of patients covered"* • *"Sounds ideal, but the beds need to be fairly distributed/accessible"* • *"There are important benefits from this potential scenario"* • *"This is vast improvement than the first two scenarios."* • *Excellent suggestions as nothing like this is available at present.* • *Do we know how many hospice beds we need for respite and for high level needs. How ever many we need, they must be accessible and well distributed across the area"*	• *"Inpatient beds must remain at St Charles"* • *"In many cases the people who need this service most are the least able to travel-either through other care commitments or through co-morbidities"* • *"Transport is a real concern and the cost of access for unpaid carers would further exacerbate their struggle with poverty. My other concern here is that this option may limit access to bereavement support which is an important part of specialist palliative care provision"* • *"Reduction in locations limits access to some families"* • *"Deeply concerned about any closures""*	• *"Community transport to take carers there and back to either location, charging would be waived for carers/family/ friends"* • *"Mix 2 and 3 for perfect solution and use of funds."* • *"Reassign/rethink the whole of the St Charles facility which is under used. It could have elderly/dementia nursing facilities with spare non medically intensive hospice facilities reducing the non-local aspect/ travel concerns for most but the highest medical intervention patients. This area could also help to take pressure off the bed blocking problems in hospitals by creating a facility for recuperation"*

Feedback on potential scenario 4: Summary

Comments	Concerns	Suggestion to improve the solution:
• *Many comments liked this scenario as it would support patients to die in a care setting environment*	• *Some comments were nervous that the required improvements in community and home care would be made in this scenario* • *Some comments were concerned how this scenario would be funded* • *Concern that there would not be enough nurses or nurses that were qualified enough*	
• *"Good but not at expense of Pembridge in house service closure"* • *"I like the nurse led patient service"* • *"Many people need respite and a nurse led unit would be good, but it must be accessible and the assessment / complex care beds also need to be in easy reach to sustain family/ carer involvement."* • *"This is probably the most practical. Most of the palliative services are nurse-led anyway by those trained in this specialty".* • *"Yes, breaking down the gaps is good, more respite care means fewer crises".*	• *"How can a nurse led service meet patient needs?"* • *"I do not want to see palliative beds reduced to 4 sites"* • *"My experience is of a family member with complex needs not met at the nursing home & therefore this option would not supply a local solution for those with similar problems"* • *"A consultant is needed . The whole point of hospice care is to have specialist help as well as general. Pembridge must be kept at a level not downgraded"*	• *"We need to pay attention to staff needs - training, support, good working conditions etc."*

Q: Is there another scenario you would like to be considered?

- **70** people answered this question
- From this number **22 people** said they did not have another scenario
- A selection of suggested alternatives can be found below (complete list found at the end of the report).

Keep the pembridge Unit open but commission an established charity who has experience of running SPC services and allow them to be creative and bold in how they deliver in-patient services, H@H and 24/7 access.
An enhanced option 2 which acknowledges population growth and an aging popula-
I don't think we should be asked to choose between the 4 options without a formal consultation and better evidence.
Think number 1 scenario for me
The current model appears to have supported generalist staff (e.g. community nurs-
Having Inpatient beds at Pembridge but providing better information and clearer access so the beds are used more. Having rapid access to out of hours advice with a dedicated help line. More use of Volunteers to support services. Exploring charitable
More co ordination with non NHS (i.e. charitable, not private sector) hospices and palliative care services.
Conducting a proper review by an independent organisation and listening and engaging with more people professionals and residents.
None of the scenarios see my comments to 3
1 and 2
all the hospices should provide in patient care, services should be available 7 days a week, the population is ageing, we need to plan to increase provision not provide fewer services
Needs big improvements from hospital to nursing homes.
Don't know
Keep all four units going and have just have 2 Specialist point of care beds in each palliative care unit to take specialist patients that have complications at the end of life
NEW, VARIED, INNOVATIVE MODEL incorporating all the voluntary, charitable systems a comprehensive choice of care and support
Can 5 hospices stay open with fewer beds. Location of hospice inpatient
Can all hospices stay open and have a mixture of special beds and some less complex beds. Locality of hospice is important to me
Some nurse led beds in each hospice
Important to remember that people get anxious and may need a bed if this allows faster access to a bed-nurse led units may be good

Email responses

A number of people commented on the future of palliative care services without answering the questions we asked, these were also an important part of the Response. The key points have been included in the summary of themes above and the correspondence itself is included in the Appendix**.**

Email correspondence was received from the following stakeholders, available to read in full in the Appendix document:

- a bi-borough response from Westminster Council and the Kensington & Chelsea Council
- Healthwatch Central & West London
- MP Andy Slaughter, Hammersmith & Fulham
- Brent Patient Voice
- Cllr Janice Long, Brent
- Hammersmith and Fulham Save Our NHS (HAFSON)

Equal opportunities monitoring

Of those who responded to the survey, the large majority identified as Female, White, British and Christian. The age range was broad between the ages of 35 up to 75 and over.

The local meetings aimed to reach out proactively to a wider more diverse group of people summarised in the table on page 7.

Conclusion

What we heard throughout the engagement period, summarised in the key themes, was that specialist palliative and end of life care services play a crucial role for people. The feedback confirmed that people really value their local specialist services and people with experience of these services are very positive about the care they have received.

We also heard that we could improve, and that these services could be available to more people, be more inclusive, adaptable and offer more choice.
The feedback indicates however that there are differing views about how we make these improvements, and create a more equitable service for all.

This programme of work is currently paused due to the current coronavirus outbreak, but it is evident that in the future we need to give opportunity for more people to engage with any proposed developments. We also need to provide more accessible information for people to be able to make an informed choice over a greater time period from all parts of each borough.

During this time The Pembridge Palliative Care in-patient unit is being used as part of the NHS health response to Covid-19 until further notice.

Support

We understand that this is an emotive issue for many people and thank you for your on-going engagement with this process.

There are a number of organisations who can offer support and counselling through bereavement and grief, we have listed some of these below.

Cruise Bereavement Care

0808 808 1677

Grief Encounter

08088020021

www.griefencounter.org.uk

Winston's Wish

08088020021

ask@winstonswich.org

Child Bereavement UK

0800 0288840

support@childbereavementuk.org

Samaritans

116 123

jo@samaritans.org

Grenfell Health and Wellbeing Centre

020 8637 6279

If you have feedback on this report we'd like to hear from you, please email nwlccgs.triborough.palliativecare@nhs.net or call 020 3350 4366.